

Table of Contents

(i

About TBI

- A General Guide to Symptoms
- Tests to Evaluate Traumatic Brain Injury
- Traumatic Brain Injury Treatments
- When Your Child's Head Has Been Hurt
- Glossary of Terms
- Facts About Comas
- When to Contact Your Doctor

The Recovery Process

- What to Expect: Stages of Recovery from an Acute Injury
- What to Expect: Stages of Recovery from Mild Traumatic Brain Injury
- Coping Strategies When a Family Member Has Traumatic Brain Injury
- Working With Your Health Care Team
- Assessment and Rehabilitation
- When Your Child Has Traumatic Brain Injury
- Back to School with Traumatic Brain Injury

Resources

- Important First Steps: What Should I Do Next?
- Where to Get Help
- Advocacy Fact Sheet



A General Guide to Symptoms

i

What is Traumatic Brain Injury?

A brain injury is any injury that results in brain cell death and loss of function. There are many ways a brain can be injured. A traumatic brain injury (TBI) is caused by an external trauma to the head or violent movement of the head, such as from a fall, car crash or being shaken. TBI may or may not be combined with loss of consciousness, an open wound or skull fracture. Brain injuries can be acute or mild and both can cause symptoms that may last for days, weeks or years.

Damage to the brain may occur at the time of injury. It may also develop after the injury due to swelling or further bleeding. Patients may have more than one type of brain injury.

Even a mild injury to the brain, sometimes referred to as a concussion, should be seen by a doctor. Most people with mild concussions are treated in an emergency department or a doctor's office. People with acute brain injuries generally stay in the hospital for further treatment.

Symptoms that May Need Further Medical Evaluation After a Brain Injury

Persons of All Ages

- "I just don't feel like myself."
- Low-grade headaches that won't go away
- Having more trouble than usual:
 - Remembering things
 - Paying attention or concentrating
 - Organizing daily tasks
 - Making decisions and solving problems
 - Slowness in thinking, acting, speaking or reading
 - Keeping track of time

Danger Signs in Adults

Call 911 immediately if you or a member of your family experiences any of the following symptoms after a head injury:

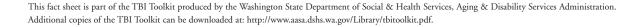
- Vomiting or dizziness
- Difficulty answering simple questions such as, "What day is it?"
- Double vision or pupils (the black part in the middle of the eye) that are different sizes
- Headaches that get worse
- Blood or clear fluid from the nose or ears
- Difficulty with walking or talking
- Seizures (convulsions, eyes fluttering, body going stiff, staring into space or a sudden onset of a fixed stare)
- Slurred speech

Danger Signs in Children

- Any of the danger signs listed for adults
- Won't stop crying
- Can't be consoled
- Won't nurse or eat

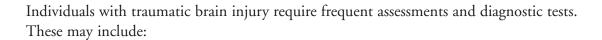
Persons of All Ages (continued)

- Having more trouble than usual:
 - Getting lost or easily confused
 - Neck pain
 - Feeling tired all the time, lack of energy
- Change in sleeping pattern:
 - Sleeping for much longer periods of time than before
 - Trouble sleeping or insomnia
- Loss of balance, feeling light-headed or dizzy
- Increased sensitivity to:
 - Sounds
 - Lights
 - Distractions
- Blurred vision or eyes that tire easily
- Loss of sense of taste or smell
- Ringing in the ears
- Change in sexual drive
- Mood changes:
 - Feeling sad, anxious or listless
 - Becoming easily irritated or angry for little or no reason
 - Lack of motivation





Tests to Evaluate TBI



- **Neurological Exam:** A series of questions and simple commands to see if the person with a brain injury can open their eyes, move, speak and understand what is going on around them. For example: What is your name? Where are you? What day is it? Wiggle your toes. Hold up two fingers. A standard way to describe responses may be used. Most hospitals use the **Glasgow Coma Scale** or **Rancho Levels of Cognitive Functioning**. You can read about these scales and what the scores mean on the back of this sheet.
- **X-ray:** A picture that looks at bones to see if they are broken (**fractured**). It can also be used to take a picture of the chest to look at the lungs. This test may be done at the bedside or in the X-ray department and takes between five and 30 minutes to complete.
- **CT Scan (CAT Scan):** An X-ray that takes pictures of the brain or other parts of the body. The scan is painless but the individual must lie very still. The test takes 15 to 30 minutes to complete.
- MRI (Magnetic Resonance Imaging)
 Scan: A large magnet and radio waves are used, instead of X-rays, to take pictures of the body's tissues. It is painless but noisy. The machine is shaped like a long tube. The individual must lie still on a flat table in the middle of the machine. The test takes about 60 minutes to complete.

- **Angiogram:** A test to look at the blood vessels in the brain. Using a catheter, or small flexible tube, dye is put into an artery (usually in the groin) that supplies blood to the brain. This test can tell if the blood vessels have been damaged or are spasming. The test takes one to three hours.
- **ICP Monitor:** A small tube placed into or just on top of the brain through a small hole in the skull. This will measure the pressure inside the brain (intracranial pressure).
- **EEG (Electroencephalograph):** A test to measure electrical activity in the brain. Special patches called **electrodes** are applied to the head to measure the activity. The test is painless and can be done at the bedside or in the EEG department. The length of the test varies.

Neuropsychological battery:

Neuropsychologists test thinking, memory, judgment, emotions, behavior and personality. This information can be used to help guide treatment. It will also help determine the amount of supervision that patients need when they leave the hospital.

Coma Scales

There are several scales used to describe the level of response in individuals with brain injury.

In acute care, the **Glasgow Coma Scale** is often used. The Glasgow Coma Scale rates eye opening, motor movement (movement of the arms and legs) and verbal response. Each response has a score. Total scores range from a low of 3 to a high of 15. The lower the score, the more complicated or severe is the brain injury.

Glasgow Coma Scale

Eye Opening

- 4 = Spontaneous
- 3 = To voice
- 2 = To pain
- 1 = No response

Best Motor Response

- 6 = Follows commands
- 5 = Localizes to pain
- 4 = Withdrawal to pain
- 3 = Abnormal extremity flexion
- 2 = Abnormal extremity extension
- 1 = No Response

Best Verbal Response

- 5 = Oriented and converses
- 4 = Disoriented and converses
- 3 = Inappropriate words
- 2 = Incomprehensible sounds
- 1 = No response

The Glasgow Coma Score is figured by adding one score from each category. Eye + Motor + Verbal = Total Score

Brain Injury	Score
Mild	13-15
Moderate	9-12
Severe	8 or less

Rancho Los Amigos Scale

Rehabilitation centers and hospitals may use the **Rancho Los Amigos Scale**. The Rancho scale measures levels of cognitive or mental functioning.

There are eight levels of cognitive functioning in the Rancho scale:

- I. No response to stimulation
- II. Generalized response to stimulation
- III. Localized response to stimulation
- IV. Confused, agitated behavior
- V. Confused, inappropriate, non-agitated behavior
- VI. Confused, appropriate behavior
- VII. Automatic, appropriate behavior
- VIII. Purposeful, appropriate behavior



TBI Treatments

The goals of treatment of acute brain injury include:

- Stop any bleeding
- Prevent an increase in pressure within the skull
- Control the amount of pressure, when it does increase
- Maintain adequate blood flow to the brain
- Remove any large blood clots

Treatments will vary with the type of injury. The doctor will decide which ones are used. Some common treatments include the following.

Positioning: Usually, the head of the bed will be elevated slightly and the neck kept straight. This position may decrease the intracranial pressure by allowing blood and cerebral-spinal fluid to drain from the brain. Please do not change the position of the bed without asking the nurse.

Fluid Restriction: It may be necessary to limit the fluids that a patient receives. The brain is like a sponge. It swells with extra fluid. Limiting fluids can help control the swelling. Please do not give fluids without asking the nurse.

Medications: There are several types of medications used to treat brain injury. Some of these include the following.

- **Diuretics** are used to decrease the amount of water in the patient's body. This makes less water available to the brain for swelling.
- Anticonvulsants are used to prevent seizures. Seizures occur as a result of extra electrical activity in the brain. There are several types of seizures. The most common type causes the

patient to have jerking movements of the arms and legs followed by sleep. Other types may cause slight tremors of the face, or staring spells. Please notify the nurse or doctor if you see any of these signs. Some patients have a seizure at the time of injury while others may develop seizures after the injury.

• Barbiturates are given if the patient's intracranial pressure is very high and hard to control. This medicine puts the patient into a deep "sleep" called a barbiturate coma. This may help prevent more swelling and damage.

Ventricular Drain (Ventriculostomy): A small tube is placed in the **ventricle**. It measures and controls pressure inside the skull. It can be used to drain some **cerebrospinal fluid** from the brain.

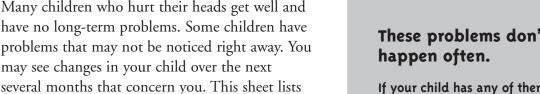
Ventilator: A machine used to support the patient's own breathing, or give the patient breaths. When the ventilator gives extra breaths, the blood vessels in the brain become smaller. This may help control the intracranial pressure.

Surgery: There are three types of surgery used with brain injury:

- Craniotomy The skull is opened to relieve the causes of increased pressure inside the skull. Causes may be fractured bones, blood clots or swollen brain tissue.
- **Burr holes** A small opening is made in the skull to remove blood clots.
- **Bone flap removal** A piece of bone is removed from the skull to relieve pressure caused by swollen brain tissue.



When Your Child's Head Has Been Hurt



some common signs that your child may have a mild brain injury. If your child has any of the problems on this list - AND THEY DON'T GO AWAY – see the "What to Do" box on the other side of this sheet.

Health Problems

Headaches

- Headache that keeps coming back
- Pain in head muscle
- Pain in head bone (skull)
- Pain below the ear
- Pain in the jaw
- Pain in and around the eyes

Balance Problems

- Dizziness
- Trouble with balance

Sensory Changes

- Bothered by smells
- Changes in taste or smell
- Appetite changes
- Ringing in the ears
- Hearing loss
- Bothered by noises
- Can't handle normal background noise
- Feels too hot
- Feels too cold
- Doesn't feel temperature at all
- Blurry vision
- Seeing double
- Hard to see clearly (hard to focus)
- Bothered by light

These problems don't

If your child has any of them, see your doctor right away.

- Severe headache that does not go away or get better
- Seizures: eyes fluttering, body going stiff, staring into space
- · Child forgets everything, amnesia
- Hands shake, tremors, muscles get weak, loss of muscle tone
- Nausea or vomiting that returns

Sleep Problems

- Can't sleep through the night
- Sleeps too much
- Days and nights get mixed up

Pain Problems

- Neck and shoulder pain that happens a lot
- Other unexplained body pain

Behavior and Feelings

- Changes in personality, mood or behavior
- Is irritable, anxious, restless
- Gets upset or frustrated easily
- Overreacts, cries or laughs too easily
- Has mood swings
- Wants to be alone or away from people
- Is afraid of others, blames others
- Wants to be taken care of
- Does not know how to act with people
- Takes risks without thinking first
- Is sad, depressed

Behavior and Feelings (continued)

- Doesn't want to do anything, can't "get started"
- Is tired, drowsy
- Is slow to respond
- Trips, falls, drops things, is awkward
- Eats too little, eats all the time, or eats thing that aren't food
- Has different sexual behavior (older children)
- Starts using or has a different reaction to alcohol or drugs
- Takes off clothes in public

Thinking Problems

- Has trouble remembering things
- Has trouble paying attention
- Reacts slowly
- Thinks slowly
- Takes things too literally, doesn't get jokes
- Understands words but not their meaning
- Thinks about the same thing over and over
- Has trouble learning new things
- Has trouble putting things in order (desk, room, papers)
- Has trouble making decisions
- Has trouble planning, starting, doing and finishing a task
- Has trouble remembering to do things on time
- Makes poor choices (loss of common sense)

Trouble Communicating

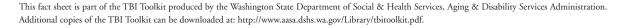
- Changes the subject, has trouble staying on topic
- Has trouble thinking of the right word
- Has trouble listening
- Has trouble paying attention, can't have long conversations
- Does not say things clearly
- Has trouble reading
- Talks too much

What to do

If your child has any of the problems on this list, and they don't go away:

- Ask your child's doctor to have your child seen by a specialist in head injury who can help your child learn skills (rehabilitation)
- Ask your child's doctor to have your child seen by a board-certified
 Neuropsychologist. This specialist can help you understand and deal with the changes in your child's behavior and feelings.
- Call the Brain Injury Association hotline for more information 1-800-444-6443.

We have only listed the problems we see most often when a child's brain is hurt. Not every problem that could happen is on this list.





Glossary of Terms

Families often hear unfamiliar medical terms. This glossary provides a sample of terms commonly used after a person has a brain injury.

A

Abstract thinking Ability to apply a concept or idea unrelated to a specific object to new situations.

Acute care Hospital with medical staff, including physicians, nurses and other staff.

Acute rehabilitation program Early phase of rehabilitation beginning as soon as patient is medically stable. Includes an interdisciplinary team of professionals.

ADL Activities of daily living (dressing, bathing, toileting, eating, etc.).

AFO Ankle-foot orthosis, a short leg brace. **Ambulate** To walk.

Amnesia Loss of memory.

Anterograde amnesia—loss of memory for events after the brain injury.

Retrograde amnesia—loss of memory for events for a period of time before the brain injury.

Post traumatic amnesia (PTA)—Amount of total memory loss after the brain injury that can range from a few seconds to months.

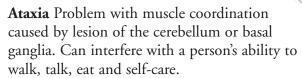
Aneurysm A balloon-like deformity in the wall of a blood vessel. The wall weakens as the balloon grows larger and may eventually burst, causing a hemorrhage.

Anoxia Lack of oxygen to the brain.

Anticonvulsant Medication to decrease possibility of seizures.

Aphasia Loss of ability to express oneself and/or to understand language that is caused by damage to brain cells.

Aspiration Fluid or food enters the lungs through the windpipe. Can cause a lung infection or pneumonia.



Attention Ability to focus on a given task or set of stimuli for an appropriate period of time.

B

Bilateral Pertaining to right and left sides of body.

Biofeedback Process in which information not ordinarily perceived (heart rate, skin temperature, etc.) is recorded and relayed back instantaneously as a signal so the individual becomes aware of any alteration in recorded activity.

Brain injury Damage to the brain that results in impairments in one or more functions.

Brain stem Lower extension of the brain where it connects to the spinal cord. Neurological functions of the brain stem are necessary for survival (breathing, heart rate) and arousal (being awake and alert).

C

Catheter A flexible tube for withdrawing fluids from, or introducing fluids into, a cavity of the body. Frequently used to drain the urinary bladder.

Cerebellum Portion of the brain (located in the back) that helps coordinate movement.

Cerebral infarct When blood supply is reduced below a critical level to a specific region of the brain and brain tissue in that region dies.

Cerebral-spinal fluid Liquid which fills the ventricles of the brain and surrounds the brain and spinal cord.

Clonus A sustained series of rhythmic jerks following quick stretch of a muscle.

Closed head injury An injury to the brain without penetration of the skull.

Cognitive impairment Difficulty with basic brain functions—perception, memory, attention or reasoning.

Coma State of unconsciousness from which the patient cannot be awakened or aroused, even by powerful stimulation; lack of any response to one's environment. Defined clinically as an inability to follow a one-step command consistently. Glasgow Coma Scale score of eight or less.

Comprehension Understanding spoken, written or general communication.

Concentration Maintaining attention on a task over a period of time; remaining attentive and not easily diverted.

Concrete thinking Unable to generalize between situations.

Concussion The common result of a blow to the head or sudden deceleration usually causing an altered mental state, either temporary or prolonged.

Confabulation Conversation which the person believes to be true though may not be, and is an attempt to fill in memory gaps.

Confusion A state in which a person is bewildered, perplexed or unable to self-orient. **Contrecoup** Bruising of brain tissue on the side opposite where the blow was struck.

CT Scan/Computerized axial tomography Series of X-rays taken at different levels of the brain that give direct images of skull and intracranial structures. Often taken soon after the injury to determine if surgery is needed. Scan may be repeated later to see how the brain is recovering.

Cue Signal or direction to help a person do an activity.

D

Decubitus Discolored or open area of skin damage caused by pressure.

Diffuse axonal injury (DAI) A shearing injury of large nerve fibers in many areas of the brain, which is a primary cause of brain injury. **Disinhibition** Inability to control (inhibit) impulsive behavior and emotions.

Disorientation Not knowing where you are, who you are or current date. Staff will often speak of being oriented three times referring to person, place, and time.

Dysarthria Difficulty forming words or speaking because of weakness or lack of coordination of muscles used in speech.

E

Echolalia Imitation of sounds or words without comprehension.

Edema Collection of fluid in the tissue causing swelling.

Electrocardiogram (ECG/EKG) Recording made by electrode pads on chest to monitor heart rate and rhythm.

Electroencephalogram (EEG) Procedure that uses electrodes on the scalp to record electrical activity of the brain.

Electromyography (EMG) Insertion of needle electrodes into muscles to study electrical activity of muscle and nerve fibers.

Emotional lability Involuntary, uncontrolled laughing or crying.

Endotracheal tube A tube that serves as an artificial airway that is inserted through the patient's mouth or nose.

Executive functions Activities controlled by the frontal lobes, including planning, prioritizing, sequencing, self-monitoring, self-correcting, inhibiting, initiating and controlling behavior.

Extremity An arm or leg.

F

Flaccid Lacking normal muscle tone; limp. **Flexion** Bending a joint.

Frontal lobe Front part of the brain; involved in planning, organizing, problem solving, selective attention, personality and a variety of higher level thinking.

Functional Ability to use skills in useful activities in a reasonable amount of time.

G

Gait training Instruction in walking, with or without equipment.

Gastrostomy tube A tube inserted through a surgical opening into the stomach. Places liquids, food or medications into stomach when person is unable to take them by mouth.

Glasgow coma scale A standardized system used to assess degree of brain impairment and to identify seriousness of injury in relation to outcome. Involves three areas: eye opening, verbal responses and motor responses.

Н

Hematoma Collection of blood in tissues or a space in the body following the rupture of a blood vessel. Types include:

Epidural Hematoma—outside the brain and its fibrous covering but under the skull. Subdural Hematoma—between the brain and its fibrous covering (dura).

Intracerbral Hematoma—in the brain tissue. Subarachnoid Hematoma—around surfaces of the brain, between the dura and arachnoid membranes.

Hemianopsia Loss of half the visual field in one or both eyes.

Hemiparesis Weakness of one side of the body. **Hemorrhage** Bleeding that occurs following damage to blood vessels.

ICP Intracranial pressure.

ICU Intensive care unit.

Impulse control Ability to withhold inappropriate verbal or motor responses while completing a task.

Incontinent Inability to control bowel and bladder functions.

Independent Ability to perform a task without assistance or supervision.

Initiation Refers to individual's ability to begin a series of behaviors directed toward a goal.

J

Jargon Spoken language that has a normal rate and rhythm but is full of nonsense words.

K

Kinesthesia Sensory awareness of body parts as they move.

L

Lability Notable shifts in emotional state (e.g., uncontrolled laughing or crying). **Lethargic** Awakens with stimulation; drowsy but awake.

Long term memory Ability to easily recall feelings, events, ideas and other information from a long time ago.



M

Medicaid State and federal program of public assistance to persons of all ages whose income and resources are insufficient to pay for health care.

Medicare Hospital and supplementary medical insurance for disabled or aged persons under the Social Security Act. **Memory** Ability to retain and recall

Mobility Ability of an individual to move within, and interact with, the environment. **MRI** Magnetic Resonance Imaging, high tech diagnostic tool to display tissues unseen in X-rays or other techniques.

N

information.

Nasogastric tube (NG tube) A tube that passes through the patient's nose and throat and ends in the patient's stomach, which can be used for feeding or suction.

Neglect Paying little or no attention to a part of the body.

Neuron Cells in the brain that send and receive information.

Neurologist A physician who specializes in the nervous system and its disorders.

Neuropsychologist A psychologist who specializes in evaluating (by tests) brain/behavior relationships; planning training programs to help the survivor of brain injury return to normal functioning; and recommending alternative cognitive and behavioral strategies.

NPO Latin initials for "nothing by mouth." This means no liquids or foods for a set period, usually in preparation for certain tests, or when the person cannot safely swallow.

0

Occipital lobe Region in the back of the brain that processes visual information.

Occupational therapy Therapeutic use of self-care, work and play activities to increase independent function, enhance development and prevent disability.

Orthosis Splint or brace designed to improve function or provide stablity.

P

Paraparesis Weakness of lower limbs. **Parietal lobe** One of the two parietal lobes of the brain located behind the frontal lobe at the top of the brain.

Perception Ability to make sense of what one sees, hears, feels, tastes or smells. Perceptual losses often are very subtle and the patient and/or family are unaware of them.

Perceptual motor Interaction of vision with motor activities, such as eye-hand coordination.

Perseveration Uncontrolled, involuntary repetition of speech or activity.

Physiatrist Physician specializing in physical medicine and rehabilitation; some are experts in neurologic rehabilitation.

Physical therapist Evaluates movement, including muscle strength, muscle tone, posture, coordination, endurance and general mobility.

Post concussion syndrome Group of symptoms after a concussion that may include memory changes, mood swings, poor concentration, headache, dizziness, depression and anxiety.

Problem-solving Ability to bring cognitive process to figuring out how to do a task. **Prognosis** Prospect for recovery from a disease or injury based on nature and symptoms of the case.

Prone Lying on stomach.

Psychologist Professional specializing in counseling, including helping people adjust to disability. Maybe uses tests to identify personality and cognitive functioning.

Q

Quadriparesis Weakness of all four limbs.

R

Random movement An action or process of moving without obvious aim, purpose or reason.

Range of motion (ROM) Active or passive movement of a joint.

Recreation therapist Responsible for developing a program to help persons with disabilities plan and manage leisure activities. Rehabilitation Comprehensive program to help individuals reach optimal mental and physical abilities or adjust to an illness or disability.

S

Seizure Uncontrolled discharge of nerve cells that may cause loss of consciousness, loss of bowel and bladder control and tremors. Usually lasts only a few minutes.

Sensation Feeling stimuli in taste, smell, hearing, vision, hearing and touch.

Sequencing Keeping track of the correct order of events for body movement and language. **Shunt** Procedure to draw off excess fluid in brain. Surgically-placed tube running from ventricles deposits fluid into abdominal cavity, heart or large veins of the neck.

Skull fracture Breaking of bones surrounding the brain. In a depressed skull fracture, the broken bone exerts pressure on the brain.

Social worker Acts as liaison between professionals and others including family, funding sources, friends and representatives of past or future placements.

Spasticity Involuntary increase in muscle tone that occurs following injury to the brain or spinal cord, causing muscles to resist being moved.

Speech and language pathology services Includes prevention, identification, diagnosis, consultation and treatment of patients regarding speech, language, oral and pharyngeal sensorimotor function.

Supine Lying on back.

T

Temporal lobes There are two temporal lobes, one on each side of the brain, located about the level of the ears. These lobes allow a person to tell one smell from another

and one sound from another. They also help sort new information.

Thrombosis A blood clot.

Tone The tension in resting muscles and the amount of resistance that is felt when a muscle is moved.

Tracheostomy Temporary surgical opening at the front of the throat providing access to the trachea or windpipe to assist in breathing.

U

Unilateral Pertaining to one side of the body.

V

Ventilator Machine that helps an individual breathe, keeps airway passages in the throat clear and provides adequate oxygen to the body.

Ventricles, brain Four natural cavities in the brain filled with cerebrospinal fluid. Outline of one or more of these cavities may change when a space occupying lesion (hemorrhage, tumor) develops.

Vocational evaluation Comprehensive process that systematically uses work, real or simulated, as a focal point for assessment and vocational exploration.

Void To urinate.

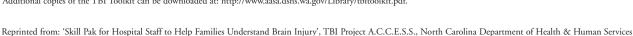
W

Wheelchair tolerance Amount of time a person is able to sit in a wheelchair, determined by the skin's response to pressure while sitting, and ability to sit without excessive fatigue.

This information may be copied and distributed. Please credit TBI Project A.C.C.E.S.S. North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services.

This fact sheet is part of the TBI Toolkit produced by the Washington State Department of Social & Health Services, Aging & Disability Services Administration. Additional copies of the TBI Toolkit can be downloaded at: http://www.aasa.dshs.wa.gov/Library/tbitoolkit.pdf.

References: Lehmkuhl, L Don. Brain Injury Glossary, the Traumatic Brain Injury Model System Research Program of TIRR. HDI Publishers, Houston, Texas. 1996







Facts About Comas

Coma, a state of unconsciousness from which a person cannot be aroused, is common following a brain injury. It is difficult for health care professionals to predict how long it may last. Characteristics of a patient in a coma include the following.

- Eyes are closed; patient looks asleep
- Does not speak or respond when spoken to
- Does not follow spoken commands
- Unaware of surroundings
- Does not respond to touch, sound or light

It is not known how much a patient in a coma hears, understands or feels. Families, visitors and staff should talk and behave as though the person can hear and understand.

Early Stages of Coma Recovery

Emerging from a coma is a gradual process of becoming more responsive and aware of people and surroundings. As the awareness improves, confusion may increase. The patient may not recognize family members or close friends. The person may become angry, shout, swear and try to hit people. Noise, light, touch or movement may trigger extreme reactions. These are normal reactions as the person emerges from a coma and are usually temporary. They are signs of progress but can be very unsettling for families to observe.

How Families Can Help During Coma Recovery

- Keep talking, noise, touching and general activity to a minimum, as these things can increase the patient's confusion and agitation.
- Give reassurance. Briefly explain what happened and state where the patient is. Repeat this, as the patient may have difficulty taking in new information and remembering it.
- Tell what time of day it is, but keep it simple.
- State who you are and who else is there.
- Touch the patient when you speak to help him figure out who you are and where you are, if this does not cause agitation.
- Bring in something familiar, such as a picture, favorite blanket or tape of a special song.
- Avoid arguing.
- Give information instead of asking questions; tell the person what to do or what is happening.
- Give visual information to help orient the patient. Post a calendar and mark off the days. Use signs as reminders of where the patient is.
- Write a short description about your family member describing their interests, likes, dislikes, family, etc. This will help the medical treatment team to know the patient better.



Measuring Comas

Glasgow Coma Scale

The Glasgow Coma Scale is a general guide for measuring the depth of coma and the alertness and responsiveness of a patient after a brain injury.

The Glasgow Coma Scale is based on measuring:

- Eye opening
- Verbal or spoken responses
- Motor or physical responses

Here's what the Glasgow Coma Scale scores:

Eye Opening

- 4 = Spontaneously
- 3 =To voice
- 2 = To pain
- 1 = No response

Best Motor Response

- 6 = Follows commands
- 5 = Localizes to pain
- 4 = Withdrawal to pain
- 3 = Abnormal extremity flexion
- 2 = Abnormal extremity extension
- 1 = No Response

Best Verbal Response

- 5 = Oriented and converses
- 4 = Disoriented and converses
- 3 = Inappropriate words
- 2 = Incomprehensible sounds
- 1 = No response

Figuring out the Score

The Glasgow Coma Score is figured by adding one score from each category. Eye + Motor + Verbal = Total Score

Brain Injury	Score
Mild	13-15
Moderate	9-12
Severe	8 or less

Rancho Los Amigos Scale

The Rancho Los Amigos Scale of Cognitive Recovery is an eight-stage scale that is widely used in hospitals and rehabilitation centers. It tracks recovery and is used to help design treatment goals.

There are eight levels of cognitive functioning in the Rancho Los Amigos scale:

I. No Response

Patient appears to be in a deep sleep and is unresponsive to stimuli.

II. Generalized Response

Patient reacts inconsistently and nonpurposefully to stimuli in a nonspecific manner. Reflexes are limited and often the same, regardless of stimuli presented.

III. Localized Response

Patient responses are specific but inconsistent and are directly related to the type of stimulus presented, such as turning head toward a sound or focusing on a presented object. He may follow simple commands in an inconsistent and delayed manner.

IV. Confused-Agitated

Patient is in a heightened state of activity and severely confused, disoriented and unaware of present events. His behavior is frequently bizarre and inappropriate to his immediate environment. He is unable to perform selfcare. If not physically disabled, he may perform automatic motor activities such as sitting, reaching and walking as part of his agitated state, but not necessarily as a purposeful act.

V. Confused-Inappropriate, Non-Agitated

Patient appears alert and responds to simple commands. More complex commands, however, produce responses that are non-purposeful and random. The patient may show some agitated behavior in response to external stimuli rather than to internal confusion. The patient is highly distractible and generally has difficulty learning new information. He can manage self-care activities with assistance. His memory is impaired and verbalization is often inappropriate.

VI. Confused-Appropriate

Patient shows goal-directed behavior, but relies on cueing for direction. He can relearn old skills such as activities of daily living, but memory problems interfere with new learning. He has a beginning awareness of self and others.

VII. Automatic-Appropriate

Patient goes through daily routine automatically, but is robot-like, with appropriate behavior and minimal confusion. He has shallow recall of activities and superficial awareness of, but lack of insight into, his condition. He requires at least minimal supervision because judgment, problem solving and planning skills are impaired.

VIII. Purposeful-Appropriate

Patient is alert and oriented and is able to recall and integrate past and recent events. He can learn new activities and continue in home and living skills, though deficits in stress tolerance, judgment, abstract reasoning, social, emotional and intellectual capacities may persist.

This fact sheet is part of the TBI Toolkit produced by the Washington State Department of Social & Health Services, Aging & Disability Services Administration. Additional copies of the TBI Toolkit can be downloaded at: http://www.aasa.dshs.wa.gov/Library/tbitoolkit.pdf.

Reprinted from: 'Skill Pak for Hospital Staff to Help Families Understand Brain Injury', TBI Project A.C.C.E.S.S., North Carolina Department of Health & Human Services References: Crowley, C. and Smith, N. 'When Your Child has a Brain Injury: What you Need to Know' Charlotte Institute of Rehabilitation & the Hembry Pediatric Trauma Institute, 1996

Houston, J, Warnock, L & Lash, M. 'Traumatic Brain Injury in Children and Teens', Dartmouth Medical School, 1998

[&]quot;About Brain Injury, Rancho Los Amigos Scale/The Levels of Coma," produced by Waiting.com, http://www.waiting.com/levelsofcoma.html



When to Contact Your Doctor



Call 911 immediately if you or a member of your family experiences any of the following symptoms after a head injury:

Danger Signs in Adults

- Vomiting or dizziness
- Difficulty answering simple questions such as, "What day is it?"
- Double vision or pupils (the black part in the middle of the eye) that are different sizes
- Headaches that get worse
- Blood or clear fluid from the nose or ears
- Difficulty with walking or talking
- Seizures (convulsions, eyes fluttering, body going stiff, staring into space or a sudden onset of a fixed stare)
- Slurred speech

Danger Signs in Children

- Any of the danger signs listed for adults
- Won't stop crying
- Can't be consoled
- Won't nurse or eat

Symptoms that May Need Further Medical Evaluation After a Brain Injury

Persons of All Ages

"I just don't feel like myself."

- Low-grade headaches that won't go away
- Having more trouble than usual:
 - Remembering things
 - Paying attention or concentrating
 - Organizing daily tasks
 - Making decisions and solving problems
 - Slowness in thinking, acting, speaking or reading
 - Getting lost or easily confused
 - Neck pain
 - Feeling tired all the time, lack of energy
- Change in sleeping pattern:
 - Sleeping for much longer periods of time than before
 - Trouble sleeping or insomnia
- Loss of balance, feeling light-headed or dizzy
- Increased sensitivity to:
 - Sounds
 - Lights
 - Distractions
- Blurred vision or eyes that tire easily
- Loss of sense of taste or smell
- Ringing in the ears
- Change in sexual drive
- Mood changes:
 - Feeling sad, anxious or listless
 - Becoming easily irritated or angry for little or no reason
 - Lack of motivation

Young Children

Although children can have the same symptoms of brain injury as adults, it is harder for young children to let others know how they are feeling. Call your child's doctor if your child seems to be getting worse or if you notice any of the following:

- Listlessness, tiring easily
- Irritability, crankiness
- Change in eating or sleeping patterns
- Change in the way your child plays
- Change in the way your child performs or acts at school
- Lack of interest in favorite toys
- Loss of new skills, such as toilet training
- Loss of balance, unsteady walking

Older Adults

 Older adults with a brain injury may have a higher risk of serious complications such as a blood clot on the brain. Headaches that get worse or an increase in confusion are signs of this complication. If these signs occur, see a doctor right away.

Source, and for more information: www.cdc.gov/\doc.do?id=0900f3ec8000d36a



What to Expect: Stages of Recovery from an Acute Injury

"How long will it take for my loved one to get better?" Your health care team may have a hard time answering this question. Age, extent of damage, length of time since injury, and past mental and physical health of the individuals all impact recovery.

The family and friends of a person with a brain injury are important members of the team. Your knowledge about the patient's emotional and physical needs is valuable, and so is your participation in helping take care of these needs.

The following are symptoms of the various stages and suggestions for things you can do that correspond with the stages of recovery.

Stage 1. Unresponsive Stage

At this stage, which you may hear referred to as a coma, the patient appears to be in a deep sleep and does not respond to the surroundings. You may notice random movements of the arms and legs. The goal during this stage is to obtain a response to touch, sound, sight or smell.

- When speaking to the patient, assume he or she understands what you are saying.
- Speak clearly and slowly in a positive, comforting way about familiar people and memories.
- When visitors are present, focus on the patient. Limit the number of visitors to one or two people at a time and keep visits short. Other distractions (TV, radio) should be turned off when visiting.

- Provide the patient with pictures, music and personal items that are comforting and familiar. Use poster board or a bulletin board near the bed.
- The nurses and therapists may encourage you to assist in care of the patient. You may be asked to help with hair care, shaving, applying skin lotion or gently stretching and positioning the patient's arms and legs. Just do what feels comfortable to you.

Stage 2. Early Responses

At this stage the patient is beginning to respond to people and hospital surroundings. The responses may range from turning toward a familiar voice to moving an arm or leg on request and following simple commands such as opening and closing eyes, sticking the tongue out or gripping and releasing hands. The goal is to increase the consistency of responses.

- There may be a delayed response time when asking the patient to move, speak or pay attention. Always wait one to two minutes for the requested response. Repeat your request only a couple of times during this time period.
- Be aware that the patient's attention span may only be five to 10 minutes before fatigue and frustration set in.
- Allow for rest periods. Turn off the TV, music and lights, and limit visitors. The patient can become stressed by too much noise, light or stimulation.
- Continue with suggestions listed in the "unresponsive" stage.



Stage 3. Agitated and Confused Responses

During this stage, things are confusing. The patient may begin to remember past events but may be unsure of surroundings and the reason for hospitalization. The individual may be confused about where he or she is and will have difficulty with memory and behavior. The goal is to help the patient become oriented and to continue to treat his or her physical needs.

- Provide one activity at a time and expect the patient to pay attention for only short periods. Keeping the noise level low helps the patient focus.
- The patient may repeat a word, phrase or activity over and over. Try to interest the patient in a different activity.
- The patient may do socially unacceptable things during this time, such as swearing or hitting. This is common. Calmly tell the patient the behavior is not appropriate.
- Remembering information from one time to another is difficult. Help orient the patient to his or her surroundings with both visual and verbal information, such as:
 - A calendar with the days marked off
 - A sign in the room telling them where they are
 - A posted schedule with meal times, therapies and special appointments
 - To decrease frustration, allow the patient to move about with supervision.

Stage 4. Higher Level Responses

At this stage the patient is able to take part in daily routines but still needs help solving problems and making decisions. Most of the suggestions from the previous stage continue to apply here. The goal is to decrease the amount of supervision needed and increase independence.

- Help make the environment safe. Safety decisions may still be difficult for the patient to make. Praise safe decisions and give calm explanations about unsafe decisions. Learning is still difficult.
- Encourage the use of memory aids such as a date book to help with appointments and daily routines.
- Encourage brief rest periods because the patient will continue to need more rest.
- Check with the health care team on activities that may be completed with or without supervision. These activities may include work or school re-entry, taking medications, driving or managing money.

Unfortunately, there is no way to predict how long a person will remain in one stage or what the final outcome will be. The team will work during the hospital stay to achieve the best possible outcome.



What to Expect: Stages of Recovery From Mild TBI

Getting Better

"Sometimes the best thing you can do is just rest and then try again later."

How fast people recover from brain injury varies from person to person. Although most people have a good recovery, how quickly they improve depends on many factors. These factors include how severe their concussion was, what part of the brain was injured, their age, and how healthy they were before the concussion.

Rest is very important after a concussion because it helps the brain to heal. You'll need to be patient because healing takes time. Return to your daily activities, such as work or school, at your own pace. As the days go by, you can expect to gradually feel better. If you already had a medical problem at the time of your concussion, it may take longer for you to recover from your brain injury. Anxiety

and depression may also make it harder to

adjust to the symptoms of brain injury.

While you are healing, you should be very careful to avoid doing anything that could cause a blow or jolt to your head. On rare occasions, receiving another concussion before a brain injury has healed can be fatal. Even after your brain injury has healed, you should protect yourself from having another concussion. People who have had repeated brain injuries, such as boxers or football players, may have serious problems later in life. These problems include difficulty with concentration and memory and sometimes with physical coordination.

Tips for Healing—Adults

Here are a few tips to help you get better:

- Get plenty of sleep at night, and rest during the day.
- Return to your normal activities gradually, not all at once.
- Avoid activities that could lead to a second brain injury, such as contact or recreational sports, until your doctor says you are well enough to take part in these activities.
- Ask your doctor when you can drive a car, ride a bike or operate heavy equipment because your ability to react may be slower after a brain injury.
- Talk with your doctor about when you can return to work or school. Ask your doctor about ways to help your employer or teacher understand what has happened to you.
- Consider talking with your employer about returning to work gradually and changing your work activities until you recover.
- Take only those drugs that your doctor has approved.
- Don't drink alcoholic beverages until your doctor says you are well enough to do so. Alcohol and certain other drugs may slow your recovery and can put you at risk of further injury.
- If it's harder than usual to remember things, write them down.
- If you're easily distracted, try to do one thing at a time. For example, don't try to watch TV while fixing dinner.



- Consult with family members or close friends when making important decisions.
- Don't neglect your basic needs such as eating well and getting enough rest.
- Make sure that your network of contacts, friends, family, co-workers understands that you're recovering from a brain injury.
- Keep the same routines.



Tips for Healing—Children

Parents and caretakers of children who have had a concussion can help them heal by:

- Having the child get plenty of rest.
- Making sure the child avoids activities that could result in a second blow or jolt to the head, such as riding a bicycle, playing sports or climbing playground equipment until the doctor says the child is well enough to take part in these activities.
- Giving the child only those drugs that the doctor has approved.
- Talking with the doctor about when the child should return to school and other activities and how to deal with the challenges the child may face.
- Sharing information about concussion with teachers, counselors, babysitters, coaches and others who interact with the child so they can understand what has happened and help meet the child's needs.
- Keep the same routines.

This fact sheet is part of the TBI Toolkit produced by the Washington State Department of Social & Health Services, Aging & Disability Services Administration. Additional copies of the TBI Toolkit can be downloaded at: http://www.aasa.dshs.wa.gov/Library/tbitoolkit.pdf.



Coping Strategies When a Family Member Has TBI

People cope with stressful situations in different ways. There are a number of feelings you and your family may experience after a brain injury.

Panic

Worries about whether your family member will survive are common during the early days after a brain injury. You may find yourself breathing rapidly, unable to sleep, having trouble eating and crying uncontrollably. These are all normal reactions.

Shock

Many families say they felt that "this can't be real." While you may be aware of what's happening around you, it may be difficult to remember information or conversations. You may have a hard time taking in what has happened and understanding all the new medical terms and procedures.

Anger

You may feel angry that this has happened. You may even find yourself angry with the individual for getting hurt. You may be angry with someone you feel has caused or been involved with the injury. Some families become angry with hospital staff and question what they are doing and how they are treating the patient.

Guilt

You may feel that you could have prevented the injury. You may find yourself thinking about how you could have done things differently or better in the past. You may even feel guilty about feeling angry. Talk about your feelings with someone you can trust. Don't struggle alone.

Isolation

You may feel distant or disconnected from others, even other family members and close friends. While you may feel that others can't possibly understand what you are going through, it's important to reach out and ask family and friends for comfort, support and help.

Hope

As the medical crisis passes, your worries about survival will change to hopes for recovery. Although any medical complications or setbacks may cause new worries, even the smallest changes or signs of progress may raise your hopes.



What are Suggestions for Coping?

What works for one person may not be helpful to another. We hope some of these suggestions will help you get through this difficult time.

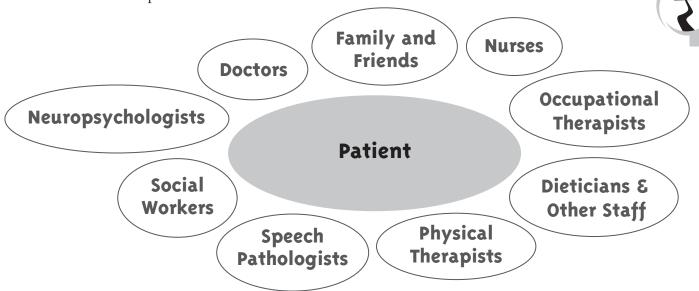
- Write important information down in a journal or notebook. You can use this to keep track of questions you want to ask members of the health care team. It may also be useful to share with the patient.
- Establish a "phone tree." Name one person for family and friends to call for information on the patient's condition.
- **Rotate family visits.** If you need or want to leave the hospital, you may want to have someone stay with the patient so you can feel reassured the patient is not alone.

- When someone offers to help, accept the offer. Try to be specific about how this person can help.
- Express your feelings. Discuss your positive and negative feelings with family members, friends and staff.
- Be kind to yourself. Take time for a walk or have a meal with a friend. Also, try to leave the hospital for a meal or restful night of sleep. It is very important to take care of yourself. By taking care of your own needs, you will be more prepared to make good decisions and support your loved one.
- Speak to a social worker, psychologist or chaplain or attend a support group.



Working With Your Health Care Team in the Hospital

Members of the health care team will work together with the patient, family and friends during the hospital stay. Care will be centered on the individual needs of the patient. Family and friends are important members of the team.



Patient: The patient is the most important member of the team. Care will be planned based on how the patient responds to treatment. Family and Friends: You provide emotional support to the patient. Family and friends also provide the health care team with important facts about the patient's past history and can help watch for changes. Other team members will show you what you can do to help with the recovery process.

Doctors: Neurosurgeons are specialists who help determine the type of brain injury and its treatment. They may perform surgery on the brain. They will work with other doctors if the patient is in intensive care or has injuries to other parts of the body. Other specialists who may care for the patient include neurologists and physiatrists. Your primary care provider may also coordinate the team.

Nurses: Nurses check patient's vitals (temperature, blood pressure, heart and breathing rate) and watch for changes in strength and thinking. They help with daily cares such as eating and bathing. Nurses also coordinate care among the members of the health care team.

Social Workers: Social workers provide emotional support to help the patient and family adjust to being in the hospital. They coordinate discharge planning, referral to community resources, and answer questions about insurance or disability.

Physical Therapists (PT): Physical therapists evaluate and treat weaknesses in the patient's strength, flexibility, balance, rolling, sitting, standing and walking. Treatment may include exercises or instruction in use of equipment such as walkers, canes or wheelchairs.

Occupational Therapists (OT):

Occupational therapists evaluate the patient's ability to perform dressing, bathing, homemaking and activities that require memory and organization. They provide treatment or equipment needed for safe independent living.

Speech Therapists: Speech therapists test and treat speech, language, thinking and swallowing problems.

Neuropsychologists:

Neuropsychologists test thinking, memory, judgment, emotions, behavior and personality. This information can be used to help guide treatment. It will also help determine the amount of supervision that the patient needs when they leave the hospital.

Dieticians: Dieticians assess nutritional needs. They work with the patient and other team members to help the patient meet their nutritional goals.

Other staff members may work with the patient and family. These include:

- Respiratory therapists
- Activity therapists
- Clergy
- Child life therapists
- Patient representatives
- Vocational counselors
- Music therapists
- Recreation therapists

Asking for information

- Ask which doctor is in charge of the patient's care. Find out the best time to talk with the doctor and how to contact him/her.
- Nurses have the most contact with the patient each day. Ask which nurse can be the communication link with you and your family. Ask whether this changes each day, evening, shift or weekend.
- Ask all therapists to describe what they do and why it is important. Ask for suggestions on what you can do between therapies to help the patient. Write down their names and contact information.
- Ask hospital professionals to tell you their names and what part they play in the patient's care.
 Writing down names may be helpful.
- Ask how the medical team will update you on the patient's progress. Arrange for a family member to be present if possible.
- Ask how to arrange meetings with doctors, therapists and specialists. You may request a meeting any time. Before any meeting, write down questions and use your notes.
- Ask how to get involved in the patient's care and how decisions about treatment will be made.

Tips for Understanding Information

- Select one person in your family to be the communications link with the hospital.
- If you don't understand something, ask that it be repeated or stated differently. Ask where you can find more information to read.
- Ask hospital staff for an interpreter if English is not your primary language. Try not to rely on family members to interpret, as this may be upsetting and difficult for them.
- Take notes or use a tape recorder (with permission) to help you remember important information and instructions.
- Ask for written information to help you understand brain injury.



Planning Ahead

- Plan the next steps with hospital professionals.
 Ask when the patient will be discharged and what problems you may expect.
- Request a list of traumatic brain injury resources to contact in the future if necessary.
- Keep copies of important information, such as consultants' reports and discharge summaries.
 Start a three-ring binder to keep them organized.

Finding A Balance

- The challenge for families and professionals is to find a balance between hope for the patient's recovery and the limitation of the current condition.
- Don't expect professionals to be able to give precise predictions for the patient's recovery.
- Know that you are on a sensitive journey where you will experience loss and gain.
- There is life after brain injury.





Assessment and Rehabilitation

Whether an individual is recovering from an acute brain injury in a hospital or a mild brain injury at home, assessment and rehabilitation can play a critical role in the recovery process.

Assessing the Injury

Assessing the injury is a key part of the rehabilitation process. Examples of physical challenges that may result from TBI include:

- Weakness and reduced motor coordination
- Speech and swallowing difficulties
- Paralysis

TBI may also affect abilities related to

- Thinking
- Problem solving
- Memory and other cognitive functions

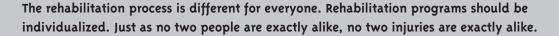
It may take several assessments to evaluate the full impact a TBI may have on overall functioning. Because emergency treatment may effect the initial assessment, it may be important to conduct additional assessments in the weeks or months following the injury.

The Role of Rehabilitation

Inpatient or outpatient rehabilitation can begin to address the brain injury issues that cause so much frustration and confusion. Research has found that patients who received inpatient rehabilitation after brain injury had better outcomes than patients who received only acute care. Outcomes were measured in the areas of functional status, daily care requirements, ability to return home and vocational status.

The goal of rehabilitation is to help people regain the most independent level of functioning possible. It's very important that therapists treating the person with TBI be trained specifically in TBI rehabilitation.

Acute inpatient hospital rehabilitation uses a comprehensive approach that includes medical stabilization, physical rehabilitation and cognitive/behavioral rehabilitation. Rehabilitation promotes learning, coping and adapting as the patient faces lifealtering changes.



Rehabilitation channels the body's natural healing abilities and the brain's relearning processes so that an individual recovers as quickly and efficiently as possible.

Rehabilitation also involves learning new ways to compensate for abilities that have permanently changed due to brain injury.



Social skills training and counseling services are provided to address the emotional and adjustment needs of the individual and family. In this environment, interaction among patients provides another opportunity for support.

Rehabilitation may be short-term (a few weeks or months) or long-term (several years). Typically, most recovery occurs within the first 12-18 months of injury, although gradual improvements may continue after that time.

Many individuals with brain injury follow a treatment course in which they initially receive acute medical, proceed to the acute level of rehabilitation and progress to more independent settings such as home with an outpatient program. Some individuals will need long term care that may occur at home or in an extended care setting.

Home and Community-Based **Treatments**

Individuals with brain injury who are able to go home may still need therapy or other care. Outpatient therapy is provided at hospitals, clinics and rehabilitation facilities. Outpatient physical therapy will help build up strength and endurance. Outpatient occupational, speech and cognitive therapy may also be needed. Family or friends may need to arrange transportation for therapy appointments. Home health care programs are available in many communities. Some of the services they offer include in-home nursing care, homemaker and health aides, meals-on-wheels, adult day care, home therapy visits, medical equipment rental/purchase and transportation.

The Continuing Role of Rehabilitation

Sub-Acute Rehabilitation

Specialized Acute Inpatient	High Intensity Rehabilitation (3-5 hours per day)
Rehabilitation	Patient actively participates

Lower Intensity Rehabilitation (< 3 hours per day) Ventilator Care

Coma Care

Post-Acute Rehabilitation Outpatient Day Treatment

In-Home Care (e.g. nursing care, rehabilitation

therapies conducted in home)

Community Re-entry Transitional Living Vocational Rehabilitation Independent Living Supportive Employment

Extended Care Skilled Nursing Facility Neurobehavioral Management

Assisted Living Adult Family Homes In-Home Services Adult Day Care

Respite Care

This fact sheet is part of the TBI Toolkit produced by the Washington State Department of Social & Health Services, Aging & Disability Services Administration. Additional copies of the TBI Toolkit can be downloaded at: http://www.aasa.dshs.wa.gov/Library/tbitoolkit.pdf.



When Your Child Has TBI

The signs of traumatic brain injury (TBI) can be very different depending on where and how severely the brain is injured. Children with TBI may have one or more of the following kinds of difficulties:

Physical disabilities

Individuals with TBI may have problems speaking, seeing, hearing and using their other senses. They may have headaches and feel tired a lot. They may also have trouble with skills such as writing or drawing. Their muscles may suddenly contract or tighten (this is called spasticity). They may also have seizures. Their balance and walking may also be affected. They may be partly or completely paralyzed on one side of the body or both sides.

Difficulties with thinking

Because the brain has been injured, it is common that the person's ability to use the brain changes. For example, children with TBI may have trouble with short-term memory (being able to remember something from one minute to the next, like what the teacher just said). They may also have trouble with their long-term memory (being able to remember information from a while ago, like facts learned last month). People with TBI may have trouble concentrating and only be able to focus their attention for a short time. They may think slowly. They may have trouble talking and listening to others. They may also have difficulty with reading and writing, planning, understanding the order in which events happen (called sequencing), and judgment.

Social, behavioral or emotional problems

These difficulties may include sudden changes in mood, anxiety and depression. Children with TBI may have trouble relating to others. They may be restless and may laugh or cry a lot. They may not have much motivation or much control over their emotions.

A child with TBI may not have all of the above difficulties

Brain injuries can range from mild to severe and so can the changes that result from the injury. This means that it's hard to predict how an individual will recover from the injury. Early and ongoing help can make a big difference in how the child recovers. This help can include physical or occupational therapy, counseling and special education.

It's also important to know that, as the child grows and develops, parents and teachers may notice new problems. This is because, as students grow, they are expected to use their brain in new and different ways. The damage to the brain from the earlier injury can make it hard for the student to learn new skills that come with getting older. Sometimes parents and educators may not even realize that the student's difficulty comes from the earlier injury.





Back to School With TBI

Susan's Story

Susan was five years old when she was hit by a car while riding her bike. She broke her arm and leg. She also hit her head very hard. The doctors say she sustained a traumatic brain injury. When she came home from the hospital, she needed lots of help, but now she looks fine.

In fact, that's part of the problem, especially at school. Her friends and teachers think her brain has healed because her broken bones have. But there are changes in Susan that are hard to understand. It takes Susan longer to do things. She has trouble remembering things. She can't always find the words she wants to use. Reading is hard for her now. It's going to take time before people really understand the changes they see in her.

What is Traumatic Brain Injury?

A traumatic brain injury (TBI) is an injury to the brain caused by the head being hit by something or shaken violently. This injury can change how the person acts, moves and thinks. A traumatic brain injury can also change how a student learns and acts in school.

What About School?

Although TBI is very common, many medical and education professionals may not realize that some difficulties can be caused by a childhood brain injury. Often, students with TBI are thought to have a learning disability, emotional disturbance, or mental retardation. As a result, they don't receive the type of educational help and support they really need.

When children with TBI return to school, their educational and emotional needs are often very different than before the injury. Their disability has happened suddenly and traumatically. They can often remember how they were before the brain injury. This can bring on many emotional and social changes. The child's family, friends, and teachers also recall what the child was like before the injury. These other people in the child's life may have trouble changing or adjusting their expectations of the child.

The term TBI is used for head injuries that can cause changes in one or more areas, such as:

- Thinking and reasoning
- Understanding words
- Remembering things
- Paying attention
- Solving problems
- Thinking abstractly
- Talking
- Behaving
- Walking and other physical activities
- Seeing and/or hearing
- Learning



Therefore, it is extremely important to plan carefully for the child's return to school. Parents will want to find out ahead of time about special education services at the school. This information is usually available from the school's principal or special education teacher. The school will need to evaluate the child thoroughly. This evaluation will let the school and parents know what the student's educational needs are. The school and parents will then develop an Individualized Education Program (IEP) that addresses those educational needs.

It's important to remember that the IEP is a flexible plan. It can be changed as the parents, the school and the student learn more about what the student needs at school.

Tips for Parents

- Learn about TBI. The more you know, the more you can help yourself and your child.
- Work with the medical team to understand your child's injury and treatment plan.
 Don't be shy about asking questions. Tell them what you know or think. Make suggestions.
- Keep track of your child's treatment. A three-ring binder or a box can help you store this history. As your child recovers, you may meet with many doctors, nurses, and others. Write down what they say. Put any paperwork they give you in the notebook or throw it in the box. You can't remember all this. Also, if you need to share any of this paperwork with someone else, make a copy. Don't give away your original.

- Talk to other parents whose children have TBI. There are parent groups all over the U.S. Parents can share practical advice and emotional support. Call NICHCY (1-800-695-0285) to locate parent groups near you.
- If your child was in school before the injury, plan for his or her return to school. Get in touch with the school. Ask the principal about special education services. Have the medical team share information with the school.
- When your child returns to school, ask the school to test your child as soon as possible to identify his or her special education needs. Meet with the school and help develop a plan for your child called an Individualized Education Program (IEP).
- Keep in touch with your child's teacher.
 Tell the teacher about how your child is doing at home. Ask how your child is doing in school.
- Give your child's teacher the tips for teachers' fact sheet.

^{&#}x27;Traumatic Brain Injury' Disability Fact Sheet Number 18, produced by the National Dissemination Center for Children with Disabilities Special needs for children with TBI including fact sheets: Tips for Teachers reprinted from 'Traumatic Brain Injury' Disability Fact Sheet Number 18, produced by the National Dissemination Center for Children with Disabilities

This fact sheet is part of the TBI Toolkit produced by the Washington State Department of Social & Health Services, Aging & Disability Services Administration. Additional copies of the TBI Toolkit can be downloaded at: http://www.aasa.dshs.wa.gov/Library/tbitoolkit.pdf.

Tips for Teachers: When Your Student has a Traumatic Brain Injury

- Find out as much as you can about the child's injury and his or her present needs. Learn more about Traumatic Brain Injury (TBI) from the many resources that exist.
- Give the student more time to finish schoolwork and tests.
- Give directions one step at a time. For tasks with many steps, it helps to give the student written directions.
- Show the student how to perform new tasks. Give examples to go with new ideas and concepts.
- Have consistent routines. This helps the student know what to expect. If the routine is going to change, let the student know ahead of time.
- Check to make sure that the student has actually learned the new skill. Give the student lots of opportunities to practice the new skill.
- Show the student how to use an assignment book and a daily schedule. This helps the student get organized.
- Realize that the student may get tired quickly. Let the student rest as needed.
- Reduce distractions.
- Keep in touch with the student's parents. Share information about how the student is doing at home and at school.
- Be flexible about expectations. Be patient. Maximize the student's chances for success.

For more information on traumatic brain injury, visit:

Brain Injury: A Guide for Families About School

http://www.bianj.org/pdf/BI guideFamilies forSchool.pdf

TBI Resources for Teachers & Parents

http://www.hospitalhome.ocps.net/tbi_parents.htm

http://www.mssm.edu/tbinet/alt/TA/techa2.html

http://www.biausa.org/Pages/for_parents.html

http://www.birf.info/artman/publish/article_familycoping.shtml

TBI in School Children

http://www.mssm.edu/tbinet/alt/TA/techa2.html

Brain Injury: A Guide for School Nurses

http://www.bianj.org/pdf/BI_guideSchoolNurses.pdf





Important First Steps: What Should I Do Next?



- Get in touch with local support groups.

 Contact Brain Injury Association of Washington http://www.biawa.org/, 1-800-523-LIFT(5438) for a list of support groups in your area. Support groups can be an invaluable resource for information on a wide variety of topics, including treatment facilities and specific programs that may be available in your area.
- Keep a daily journal of mental and physical changes. Keep a list of questions for the doctor or others on the treatment team. Keep track of treatments, medications and results.
- Establish a support system of family and friends. Organize family and friends to visit the individual who has been injured, support the family and help with tasks needed to prepare for the future.
- Contact the case manager at your hospital. Identify the case manager and discuss the individual's progress and potential needs after discharge. Get help in identifying supports and services that may be available.
- Apply for Supplemental Security Income (SSI)

 /Medicaid immediately. SSI is a program of the
 Social Security Administration that provides
 monthly payments to people who are, among
 other qualifiers, disabled and have limited income
 and/or resources. Parents need not be eligible
 themselves in order for a disabled child to receive
 SSI. If eligible, the individual usually can get
 Medicaid health insurance, which is tied into the
 SSI benefits package. Contact your local Social
 Security office for more information.

- Apply for Social Security Disability
 Insurance (SSDI)/Medicare immediately.
 SSDI provides monthly payments for workers and eligible members of their family if an illness or injury is expected to keep workers off the job for a year or longer. Medicare is a health insurance program tied into SSDI. A new beneficiary must wait 24 months after SSDI benefits begin before receiving Medicare coverage, in addition to the five-month waiting period after the onset of the disability. Enrollment in the Medicare program is automatic for SSDI recipients, no application process is needed. Discuss this with your care manager or contact your local Social Security office for more information.
- Talk with your hospital case manager about services for which the patient may be eligible.
 The case manager will be able to provide you with appropriate services to help the recovery process.
- If a school-age child has been injured, contact the school immediately. If the individual is in school, arrange with the school's principal when the student can return to school or alternate services while absent from school. If the student is in college or technical school, contact the school's Disability Office.
- Protect the ability to make decisions. If there is concern about the person's ability to consent to treatment, get information from Washington Protection & Advocacy System (WPAS) at 1-800-562-2702 about alternatives to guardianship, substitute decision-making and guardianship. Often you can avoid the expense and loss of rights that occur with a guardianship by looking at less drastic steps.



Where to Get Help

Help for People with Brain Injuries

"It was the first time in my life that I couldn't depend on myself."

There are many people who can help you and your family as you recover from your brain injury. You don't have to do it alone. Take this information to your doctor or health care provider and talk with them about your concerns. Ask your doctor whether you need specialized treatment and about the availability of rehabilitation programs. Your doctor may be able to help you find a health care provider who has special training in the treatment of concussion. Early treatment of symptoms by professionals who specialize in brain injury may speed recovery. Your doctor may refer you to a neurologist, neuropsychologist, neurosurgeon or specialist in rehabilitation.

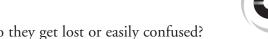
Help for Families and Caregivers

"My husband used to be so calm. But after his injury, he started to explode over the littlest things. He didn't even know that he had changed."

When someone close to you has a brain injury, it can be hard to know how best to help. Individuals with brain injuries may say that they are "fine" but you can tell from how they are acting that something has changed.

If you notice that your family member or friend has symptoms of brain injury that are getting worse or are not getting better, talk to the individual and his or her doctor about getting help. Family members may also need help if you can answer YES to any of the following questions:

- Has their personality changed?
- Do they get angry for no reason?



- Do they get lost or easily confused?
- Do they have more trouble than usual making decisions?

You might also want to talk with people who have experienced what you are going through. The Brain Injury Association can put you in contact with people who can help.

Resources for Getting Help

"I thought I was all alone, but I'm not. There are lots of people out there who understand what I've been through."

Several groups help people with brain injury and their families. They provide information and put people in touch with local resources, such as support groups, rehabilitation services and a variety of health care professionals.

Among these groups, the Brain Injury Association (BIA) has a national office that gathers scientific and educational information and works on a national level to help people with brain injury. In addition, 44 affiliated state Brain Injury Associations provide help locally, including one in Washington State.

You can find more information about traumatic brain injury by contacting:

- Brain Injury Association, National Help Line: 1-800-444-6443, Web site, www.biausa.org
- Brain Injury Association of Washington, www.biawa.org
- Centers for Disease Control and Prevention Web site: www.cdc.gov/ncipc/tbi
- TBI ARMS Traumatic Brain Injury Advocacy, Resource, Mentoring Services, 360-387-6428, or toll free at 1-877-205-9177



Advocacy Fact Sheet

How to Get What You Need

Many systems do not understand brain injury and persons with TBI often need an advocate to help them get the services they need, beginning as soon as they are injured. As well as helping to obtain services, an advocate can assist with day to day issues such as helping to correct a phone bill error. An advocate can be a family member, friend or neighbor, and sometimes the need for help from an organization that specializes in advocacy, or even a lawyer, may be necessary. Your social worker, case manager or religious leader may also be able to help with advocacy needs.

Organizations that Can Help

Advocacy organizations can help persons with TBI and their families determine what services they qualify for. Many informal support groups focus on advocating for rights of people with TBI or other disabilities. There also are professional organizations that focus on enabling individuals with disabilities.



Who to Contact:

- Washington Protection & Advocacy System (WPAS), 800-562-2707, TTY: 800-905-0209, www.wpas-rights.org WPAS provides free advocacy services to people with all kinds of disabilities. Contact WPAS for:
 - Disability rights information
 - Information and referrals
 - Problem solving
 - Community education and training
 - Problems accessing services because of traumatic brain injury
 - Legal services for disability discrimination or violation of your rights
 - Discrimination, abuse or neglect against someone with a brain injury

You can also get information about advocacy and brain injuries from:

- Brain Injury Association of Washington, www.biawa.org
- Brain Injury Resource Center, www.headinjury.com
- TBI ARMS Traumatic Brain Injury Advocacy, Resource, Mentoring Services, 360-387-6428, or toll free at 1-877-205-9177

Developing an Advocacy Plan

Learning to become a skilled advocate on behalf of an individual with brain injury takes time and practice. You can start the process on behalf of yourself, or a family member by developing an advocacy plan. Steps to an advocacy plan include:



Assess the problem

- Break down the problem
- Set goals
- Recognize biases
- Decide what it is you want to happen

• Form an advocacy team

 Find allies, people who will support your efforts

Gather information and form solutions

- Research relevant policies, laws and complaint processes
- Examine what's been done
- Research opposing views

• Choose advocacy strategies

- Create a paper trail
- Start with low-level solutions
- Move on as needed to more involved advocacy approaches, such as legal aid or media relations

• Write your plan

- Start with a solution
- Break down steps to reach the solution
- Organize and prioritize activites
- Evaluate progress
- Look for new allies

• Evaluate and follow up

- Make sure you have agreement
- Look for other advocacy needs
- Evaluate plan